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Mapping experiences of pathological demand avoidance in Ireland

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Key words: Autism, anxiety, demand avoidance, families, practitioners, education, healthcare.

Pathological demand avoidance (PDA) is contended to be a distinct presentation within autism characterised by extreme levels of anxiety in response to the demands of everyday life, manifested in excessive levels of demand avoidance. This results in complex interactions with service providers in education and health settings, impacting on outcomes for individuals and their families. This national study sought to gather the viewpoints of individuals who experience PDA, families, and practitioners, with the intention of determining levels of knowledge, recognition and understanding of PDA; exploring current pathways to assessment and diagnosis; capturing experiences of access to education and healthcare services; identifying effective intervention and support strategies; and illuminating education and health outcomes for individuals and families. This mixed-method study collates survey responses from N = 264 parents, N = 9 life partners, N = 6 individuals experiencing PDA and N = 54 practitioners, and in-depth individual and focus group interviews from these cohorts. Findings suggest that a flexible, informed and individualised approach to assessment and service provision for individuals presenting with a PDA profile is essential. Practitioners universally referred to the necessity for a streamlined, integrated and multi-disciplinary approach. The reported disconnect between education and health systems indicates a need for access to services on an equitable basis.

Background

Pathological demand avoidance (PDA) is believed to be an extreme, anxiety-based profile within the autism spectrum that is ‘pathological’ in that it permeates all aspects of daily life both within the family context and the wider social environment (Newson, 1990; Newson, Le Maréchal and David, 2003). It is characterised by a resistance to ordinary, everyday demands, use of socially manipulative avoidance strategies, extreme lability of mood, obsessive behaviour and immersion in role-play as a method of avoidance (Christie, 2007; O’Nions et al., 2016). Whilst not formally recognised within diagnostic instruments (e.g., ICD-11; DSM-V), PDA is a contested and debated concept (e.g., Milton, 2013; Moore, 2020), where Intolerance of Uncertainty and accompanying anxiety are proposed as elements that can explain extreme demand avoidant behaviours (e.g., Rodgers et al., 2016; Stuart et al., 2019). However, there is growing acknowledgement of PDA by entities such as the National Autistic Society and Autism CRC in Australia, with the PDA Society (2022) recently publishing practice guidance for identifying and assessing for a PDA profile.

The incidence of autism within the population of Ireland is currently estimated to be 1 in 65 (HSE, 2018), with a suggested prevalence of PDA of 1 in 5 within an autism community (Gillberg et al., 2015). Rodgers (2019) points out that between 22% and 84% of autistic children and 35% to 77% of autistic adults report anxiety, with 50% of children describing impacts on daily life. Despite the contested nature of PDA, a parent support group in Ireland hosted on Facebook has now accumulated over 1000 members. This is not only an important phenomenon and reflects the desire for knowledge but also an affirmation of the challenges experienced by families in the face of historical parent blame (Silverman and Brosco, 2007). Inevitably, this has broader implications in terms of parental stress and family circumstances (Gore-Langton and Frederikson, 2018).

The separation of disability services and mental health services for autistic children and young people means that the overlap of extreme anxiety and autism is not addressed, with children and families bounced between services (HSE, 2018; Lynch, 2019) and is reflective of the dissonance surrounding the separation of mental health and autism (White et al., 2009). Currently, access to diagnostic pathways for children with disabilities has reached an impasse, with at least 4000 children still awaiting an assessment of need under the Disability Act (Government of Ireland, 2005) with many more having ‘aged-out’ of waiting lists (Ombudsman for Children, 2020). Moreover, where an assessment of need results in referral to a further waiting list, education and healthcare services are not accessible to all on a comparable basis nationwide (Smith et al., 2019). Within education contexts, recent investigations of school exclusion and reduced timetables imposed on families of autistic children in Ireland (ASIAM, 2019; Brennan and Browne, 2019; Inclusion Ireland, 2019), highlight a practice that results in interrupted education and at worst the cessation of meaningful engagement with schooling which creates additional stressors for families (Hatton, 2018; Lyle and Leatherland, 2018; Preece and Howley, 2018).

The objectives of this present study were to (1) conduct a national survey of Ireland to establish the degree of prevalence of PDA and the extent of access to diagnosis, support services or educational and clinical intervention opportunities for individual or their families and (2) use semi-structured individual interviews and focus groups to capture the lived experience and impacts of PDA from the perspective of individuals, families and supporting professionals. Consequently, this study takes as its conceptual framework an adapted model of bioecological systems theory (Bronfenbrenner, 1993; Bronfenbrenner and Morris, 2006) to illustrate how the relationship between political, economic, social and cultural systems can and do impact on education, health – and by extension – life outcomes, for the autistic community in Ireland.

Theoretical framework

Greenfield (2012) discusses the utility of ecological frameworks as they ‘focus attention to the mutually influential and dynamic transactions among individuals and diverse environmental contexts that shape continuity and change in functioning across the life span’ (p. 2). In reconceptualising Bronfenbrenner’s bioecological model for inclusive education, Anderson, Boyle and Deppeler (2014) draw attention to the role of inclusive principles, namely, participation (citing Booth and Ainscow, 2002), achievement (citing Guskey, 2013) and value of person (citing Aspin, 2007) placing these at the core of the Microsystem.

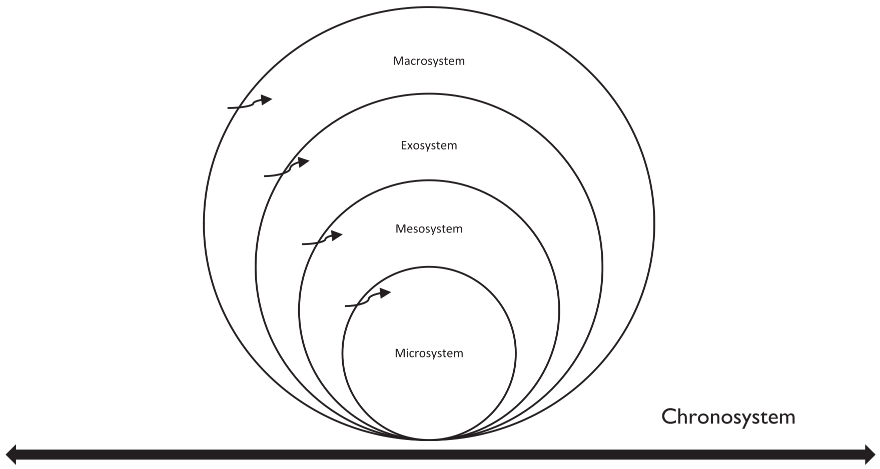
This model can be adapted to illustrate systemic influences by various national and local agents and agencies (Figure 1). In Ireland, the macrosystem is influenced by such as the United Nations Conventions on the Rights of the Child (UNCRC; UN General Assembly, 1989) and People with Disabilities (UNCRPD; UN General Assembly, 2006) and national legislation, for example the Education for Persons with Special Educational Needs Act (EPSEN; Government of Ireland, 2004), the Disability Act (Government of Ireland, 2005) and the Education (Admission to Schools) Act (Government of Ireland, 2018), which inform national policies administered by the National Council of Special Education (NCSE).

If we extend this thinking and map PDA onto these contexts, it is possible to more clearly understand how and why pathways to assessment, diagnosis, suitable education placements and appropriate interventions may be complex, interrupted, circuitous or suspended. Examining school exclusion and autism from a nested systems perspective also illustrates the very real difficulties encountered by families in pursuit of an education for their children.

It is also important to set these challenges against a background of unequal access to health and social care across counties (Smith et al., 2019); limited support from agencies such as the National Educational Psychology Service (NEPS) – approximately 5000:1 pupil to psychologist ratio (Houses of the Oireachtas, 2021); the introduction of a new School Inclusion Model available to only 75 primary, post-primary and special schools, and 75 pre-school settings associated with primary schools participating in the project (NCSE, 2017, 2020); and declining numbers of experienced teaching and support professionals (O’Doherty and Harford, 2018). Furthermore, the co-occurrence of autism and mental health conditions is well documented, yet management of this overlap in conditions in Ireland is compartmentalised between health and disability services, where people with autism ‘find it harder to access services, with an over-focus on their autism when they do access them, leaving mental health conditions under-diagnosed and under-treated’ (Harris, 2019, cited by Lynch, 2019). Thus, providing clear, evidence-based advice to the ecology that surrounds and supports individuals with PDA and their families or life partners, was an important ambition of this study.

Rationale

The dearth of PDA research in Ireland and awareness and understanding of anxiety-based demand avoidance in general, arguably impacts on pathways to assessment and diagnosis, which in turn determine access to support in education and healthcare settings. *Mapping experiences of pathological demand avoidance* was commissioned by Prism DLR an autism charity in Ireland to gather the viewpoints of individuals identifying as PDA, families and practitioners with the intention of (1) determining levels of knowledge, recognition and understanding of PDA, (2) exploring current pathways to assessment and diagnosis, (3) capturing experiences of access to education and healthcare services, (4) identifying effective intervention and support strategies and (5) illuminating education and health outcomes for individuals and families in Ireland. The intended outcomes were to disseminate findings in key locations across the country, enable a national conference to encourage public debate between individuals, families and practitioners and to develop evidence-informed strategies to support and manage anxiety-based demand avoidance at home and in school.



Macrosystem
Legal frameworks and definitions e.g. UNCRC, UNCRPD, Education for Persons with Special Educational Needs Act, Disability Act, School Admissions Bill, Autism Bill, National Council for Special Education policies, directives from teaching unions, teacher training standards.

Exosystem
Primary and secondary education: physical infrastructure, sensory environments, autism units / autism classes, reverse inclusion, National Educational Psychology Service Continuum of Support, models of resource allocation, role of Special Needs Assistants (SNA), teacher / SNA upskilling and training.

Mesosystem
Access to an appropriate school setting; availability of SNA support; school ethos and culture; autism awareness-acceptance-understanding; implementation of Individual Education Plan; home-school communication; management of transitions; school policies e.g. uniforms and homework.

Microsystem
Feeling valued and accepted; opportunities to participate with peers; individualised approaches to facilitate achievement; relationships within the school community; implementation of sensory diet; access to therapies; parental resources and input; idiosyncratic autism profile; anxiety and school attendance.

Chronosystem
Physiological, emotional and cognitive development; social and cultural thinking; economic booms and recessions; educational and medical approaches; research; activism.

↗ **Impact events:**
Changes in personal circumstances e.g. parental unemployment, homelessness; changes in / additions to autism diagnosis e.g. mental health; change in medication; changes in support teams e.g. new teachers, clinician; management of micro (between classes) and macro (between education placements) transitions.

Figure 1: Bioecology of autism, education and health care in Ireland

Method

This mixed-method study utilised quantitative data analysis from an online survey complemented by semi-quantified thematic analysis of open-ended survey questions and in-depth, semi-structured individual interviews and a focus group.

Sample

A self-selecting probability sample of 335 individuals participated in the online survey comprising of parents (N = 264), life partners of autistic individuals who experience PDA (N = 6), and autistic individuals self-identifying as experiencing PDA (PDAers: N = 11) and education and healthcare practitioners (N = 54). This latter group included health professionals (Clinical and Counselling Psychologists, Speech and Language Therapists, Occupational Therapists, General Practitioner and Nurse), education practitioners (Educational Psychologist, Teachers and Special Needs Assistant) and social care (Social Worker and Home Support Workers). Within the teacher cohort, responses were recorded from pre-school (Montessori), primary and post-primary mainstream settings.

Instruments

The study used a mixed method (Creswell, 2009; Creswell and Plano Clark, 2007, 2011) in that qualitative and quantitative approaches were used simultaneously with no priority given to either method of data collection or analysis. A self-administered online survey was adapted from the 'Being Misunderstood' (PDA Society, 2018) with permission granted to replicate the survey in Ireland for comparative purposes. Some small amendments were made to reflect differences between systems and terminology between the UK and Ireland. This data was augmented with in-depth semi-structured interviews with self-selected individuals living with PDA (N = 2), life partners of individuals living with PDA, practitioners diagnosing and supporting children and adults with PDA (N = 2); one education professional (secondary teacher) and one healthcare practitioner (psychologist) and parents, carers or guardians of children and adults with PDA (individual interviews N = 5); focus group participants (N = 4). The survey and interview schedule were premised upon five inter-related *a priori* themes: (1) awareness, acknowledgement, acceptance and understanding PDA, (2) journeys to assessment and diagnosis, (3) access to education and health services, (4) approaches and interventions for management and support, (5) education, health and life outcomes and (6) triumphs and challenges.

Data analysis

Descriptive statistics were extracted from a quantitative analysis of survey data using a statistical software package (SPSS); open-ended survey responses and interview data were themed and quantified to record prevalence of experiences and viewpoints. A hybrid approach to thematic data interpretation (Fereday and Muir-Cochrane, 2006; Swain, 2018) was adopted to examine inter-related themes. Subsequently, transcripts were thematically analysed, categorised and re-categorised on three separate occasions. Data from individual interview transcripts were also used to illustrate individual pathways and outcomes for some children and their families and presented as vignettes within the findings of the final report.

Procedure

The survey was shared across existing networks of autism-related charities in Ireland and on a range of social media platforms. Additionally, information leaflets and invitations to participate were displayed in health and mental health service settings and public libraries. Participants who subsequently self-selected for interview received a set of trigger questions. At the request of participants, interviews were conducted either by telephone or in person and digitally recorded; transcripts were approved by participants. The text corpus retrieved from free response survey items and interview transcripts was thematically coded using NVivo software in three separate passes and reviewed by both researchers.

Results

Understanding and awareness

Only 37% of professionals believed that they had a good understanding of the presentation of PDA, and 22% indicated no understanding at all. Some practitioners refer to this profile as Oppositional Defiant Disorder or Conduct Disorder, arguably demonstrating a misunderstanding of the underpinning argument for PDA. Parent/carer respondents (63%) believed that professionals were 'rarely' or 'never' aware of PDA, and a common theme arising was reference to poor parenting skills (45%) and attachment issues (27%) as key contributors to demand avoidance, with parenting courses cited as the first-line response to challenging behaviour or school avoidance, with: 'A focus on helping me "cope" instead of getting my son the services he needs' (Parent, survey). Parents supporting adult PDAers report similar experiences which extend beyond childhood and adolescence.

Journeys to assessment and diagnosis

The majority of practitioners surveyed (83%) use PDA terminology with some reporting that they use functional assessment and terminology to describe behaviour or presentation as being 'consistent with a diagnosis of pathological demand avoidance, which is a specific form of ASD characterized by…' followed by a statement of key features. Additionally, 34% reported using diagnostic terminology associated with mental health; some refer to this profile as Oppositional Defiance Disorder (ODD) and Conduct Disorder. Arguably, one of the difficulties with the removal of distinct profiles (e.g., Pervasive Developmental Disorder NOS) within DSM, is that practitioners must utilise banded criteria which do not describe atypical presentations of autism and consequently, there is a reluctance to utilise descriptive categories which are not formally recognised: 'You know, they could be more flexible, as in, they could say, you know, anxiety-driven, or hint towards PDA … So that's the frustrating bit, it's like, you know, you're telling us it is, you acknowledge it, say it is, but yet, you're refusing to put it in writing' (PDA Adult, interview).

Only 25% (N = 46) of parents and carers had received a formal diagnosis of PDA for their child with N = 119 reporting that the PDA profile described their child, and a further 61 reported a presentation of extreme anxiety and intolerance of uncertainty.

Access to education and health services

N = 165 parents and carers reported barriers to accessing support for their children, almost 60% of whom were attending mainstream education, 8% being educated at home *via* the Department of Education Home Tuition scheme; of concern, 11% were reported as not receiving any education at all. In terms of whether supports/interventions provided in education or healthcare settings had positive outcomes, 29% of parents believed that they were not so effective, and 33% not at all effective. Occupational therapy, Speech and Language Therapy and Play Therapy were the most frequently accessed and most effective of all interventions.

Approaches and interventions for management and support

Professionals described challenges in working with CYP principally connected to lack of knowledge and training, specifically in relation to managing unpredictability of mood, sensory dysregulation, aggression in response to demands, working with an absolute need to control, an absence of sense of self, inefficacy of most frequently suggested autism strategies and inappropriate educational placements. Notably, however, formal information avenues and training opportunities were principally provided by charitable institutions such as the PDA Society (UK) and Prism DLR (Ireland) (36%), incidental talks (24%) and Internet searches (18.5%), with 17% indicating no access to training for PDA. Despite these challenges, in both survey and interview, practitioners demonstrated not only awareness and understanding of PDA, but imagination and creativity in their approach to intervention and support.

Of the N = 173 parents who answered the question regarding educational provision, 88% had received educational supports for their child. Cross-tabulation of survey data indicates that the bulk of intervention is received during primary school years, with decreasing levels of support into secondary education. In terms of whether supports or interventions provided in education or healthcare settings positively affected their child's difficulties, 29% of parents believed that they were not so effective, and 33% not at all effective.

Education, health and life outcomes

Parent/carer reports of challenges experienced by CYP indicate a significant and complex interplay between sensory/cognitive/behavioural factors, in particular the relationship between sensory issues (81.42%), need to feel in control (81.82%) and severe anxiety (78.26%) which may be impacting on difficulties with daily routine (67.59%), school absence (52.57%) and problems sleeping (56.52%). Additional Chi-square analysis showed that girls were more likely to experience difficulties in daily routines (71%) than boys (63%) (X^2 (1, N = 222) = 4.27, $P < .05$) and that older girls (77%) were significantly more likely than older boys (52%) to experience difficulties in daily routines (X^2 (1, N = 81) = 4.50, $P < .05$). There are also significant differences in the type of challenge experienced by children depending on their age; survey data indicates that N = 142 children attended preschool to end of primary school (ages 3–12 years), N = 82 attending post-primary school (13–18 years). Younger children were significantly more likely to experience sensory issues (89%) than older children (68%), to have a greater need for control (88%) than older children (70%) and to exhibit challenging behaviours (85%) than older children (68%).

However, examining the potential relationship between the most commonly experienced challenges and parental well-being, we found a significant relationship between children's experience of extreme anxiety (X^2 (1, N = 162) = 5.38, $P < .05$) and experience of sensory issues and parental well-being (X^2 (1, N = 162) = 5.38, $P < .05$). The impact of sensory issues on parental well-being seems to be related to children's age, with a greater proportion of parents of older children with sensory issues reporting impact on their well-being suggesting that while sensory and anxiety issues are more prevalent among younger children in the study, where these are experienced by older children, they have a greater impact on parental well-being. Supporting a family member with PDA impacts negatively on parent/carer well-being (69%), emotional and mental health (86%), sleep dysregulation (78%) and physical health (59%). Inevitably this affects parent/carer relationships (78%) and the family dynamic (85%).

Those parents and carers who reported a negative impact on emotional well-being were significantly more likely to also report that supports for PDA were ineffective. Specifically, impact on well-being seems to be related to (1) the quality/effectiveness of supports received, (2) the type of specific challenges experienced by the child and potentially (3) the age of the child. The impact of poor parental mental and physical health, together with the need to support vulnerable and distressed children, also has an economic effect on the family: 35% of parents stated that they had left their job as a result of the impact of caring responsibilities or had reduced working hours (18%), or had taken a less challenging job (11%). Despite this significant impact on household income, 66% of families are not in receipt of Carer's Allowance.

Life partners report significant challenges in providing care and support, emphasising the urgent need for health professionals to acknowledge the long-term stress: on relationships 'It was so difficult to cope, I thought I was going mad. The arguments went on and became very intense. He has not had a steady job since we got married, until now, and still, he constantly talks about leaving the job, and he flares up if I argue back'. PDA adults repeatedly emphasised the need for greater acceptance of the way in which they experience and view the social world and consideration of the consequences of imposing rigid structures of support or categorically specific models of service provision.

Triumphs and challenges

Parents, guardians, carers and life partners (25%) stated that enjoying their child's unusual and quirky personality and company was rewarding, as was observing progress through achievement of previously unmanageable tasks, the development of self-awareness and self-management and learning from their child resulting in improved understanding of their perspective. However, they identified lack of awareness, recognition, understanding and support as their most significant difficulty (Figure 2).

Parents also referred to managing their own exhaustion and stress, dealing with violent and aggressive behaviour, getting though daily life, the effects on siblings and other family members and getting their child into school.

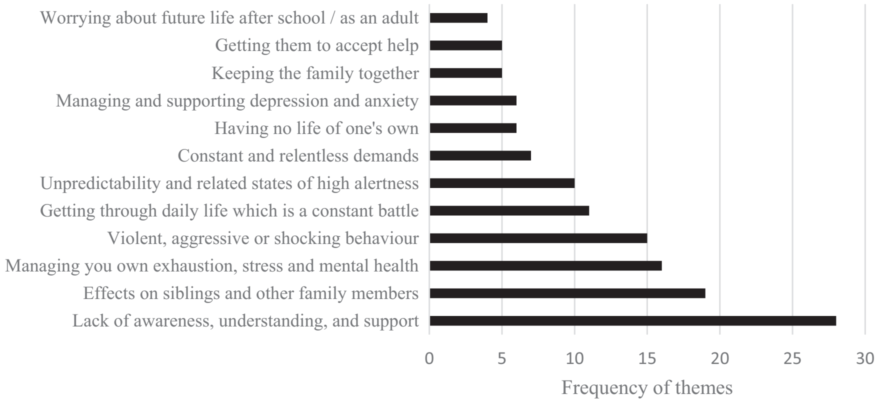


Figure 2: Parent viewpoints on the challenges of PDA

Practitioners identified challenges to working with individuals with PDA (Figure 3) as understanding the underlying cause of anxiety and avoidance, utilising strategies that run counter to typical approaches, emotional dysregulation, unpredictability and mood swings and lack of understanding – and willingness – from colleagues to try alternative approaches.

One adult PDAer talked at length about the challenging nature of the education system, whereby: '. . . the extent to which education is the foundation from which all supports for life are built . . . for everyone – the difference is that ye normal lot really are ok with an approximate "one size fits all" that is toxic to us'. Furthermore, they argue that supports are:

> '. . . all centred on what do you need people to help you with . . . most autistics need extra money to help them avoid people. They will pay for a companion to travel with you, but they won't pay for a car so you can travel in isolation, which is essential to me or I would be housebound. They lock us up in isolation to contain us, but nobody has ever tried leaving us alone constructively.'

Discussion

Practitioners accept the contested nature of PDA, and that its perception as a construct is nuanced rather than absolute; this lack of clarity is reflected in the inconsistency within the assessment and diagnosis process more generally.

> 'If the diagnoses were included in the DSM and ICD classifications, then the diagnoses would have more traction with clinicians, and this would trickle down into the school systems as well as the adult ASD systems. This would ensure statutory recognition and henceforth more formalised training from the HSE and other statutory groups to alleviate the responsibility of dissemination of information, which currently rests with the community/voluntary sector.' *(Practitioner, psychologist)*

Fundamentally, awareness and acceptance within the autism community – and PDA groups in particular – provide affirmation and support for families that is essential for their own mental health and well-being. The principal challenge for assessment of PDA as reported by practitioners, is connected to a lack of formal recognition within diagnostic instruments. This impacts on service provision and allocation of resources to support health and education as is the case for the autistic population generally in Ireland (HSE, 2018). Lengthy waiting lists across the country are a significant barrier to timely assessment and diagnosis (Ombudsman for Children, 2020) leaving parents to work in a vacuum: 'The OT said he was demand avoidant and

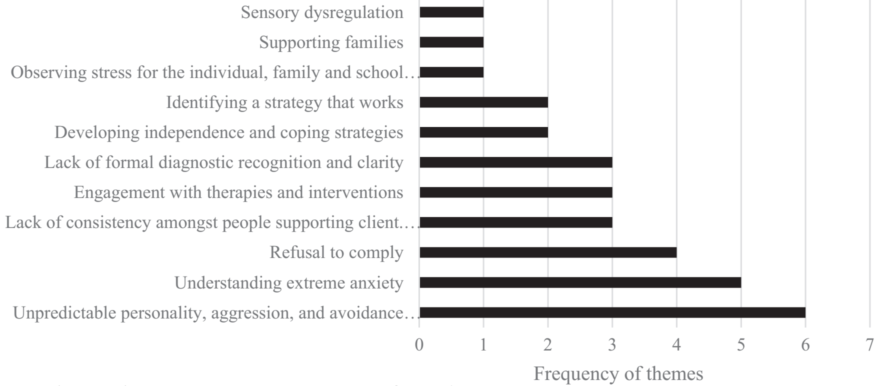


Figure 3: Practitioner viewpoints on the challenges of PDA

sensory issues etc. 18 months now till psychology start seeing him and he potentially gets support. They said 2 yrs wait now for assessment' (Parent, survey).

In Ireland, a new model introduced by the National Council for Special Education NCSE (2017), set out a framework for allocation of special needs resources to schools that no longer depends upon a formal diagnosis of SEND. However, children and young people (CYP) with highly specific needs are at risk within such a model where the detail provided within professional assessment is crucial to individual, person-centred intervention: 'I would be teaching in a very big school . . . our hands are tied in that sense, and people are trying to do everything that they possibly can on the ground, but there is a problem getting resources, if there isn't a diagnosis and if there isn't a report coming from the primary school' (Teacher, interview).

Provision of services to CYP are siloed between Disability Services and CAMHS, meaning that autism and anxiety are treated as separate conditions requiring intervention from different entities. This was repeatedly noted within survey comments and interviewees representing the most significant barrier to achieving a multidisciplinary diagnosis that would speak to all aspects of need: '. . . the anxiety that comes with autism, fits into mental health, but autism fits into the disability team, there is no specific in-between version in autism mental health, so, you know, the child doesn't fit neatly into a box' (Parent, focus group).

Practitioners across a range of settings repeatedly referred to the need for avenues for professional discussion and collaboration, input from multi-disciplinary teams, and more understanding from colleagues due to the complexity of the PDA profile: 'Are other professionals concerned that we might not get the right balance and the child may be denied learning opportunities (academic, life skills, behaviour, emotional management) that he/she is able for, or we may ask too much of the child to his/her detriment?' (Psychologist, survey).

Many parents acknowledged the efforts made by schools to accommodate individual needs and establish effective strategies: 'I can't even tell you how much reaching out they've done already, absolutely stunning amount of support from them' (Parent, survey). These good intentions are often sabotaged by frequent changes to teaching staff, slow uptake of recommended strategies, or failure to pass on information to teachers in subsequent years, or to transmit information from one school to another. Notwithstanding, many parents credited schools with researching approaches and strategies to manage PDA and the gradual acquisition of a knowledge bank that should be supported with increased training and CPD. Most significantly, parents reported that once individuals have transitioned out of formal education, support dissipates to extremely low levels. This is of concern given the complexity of transition into adulthood, a critical period as individuals is exited from child services into uncertain futures, therefore, gaps in support in adolescence compromise already vulnerable individuals.

Education, health and life outcomes evidence the significant impact of all other themes in this study. Parents of adult children describe lifelong impacts as a result of lack of care and support, resulting in poor outcomes and restricted life skills: 'He has never kept a job for more than a few weeks and his refusal or inability to engage with any official bodies and services means he is treated as unemployed, not having a disability, and so receives no money or financial support. He is supported entirely by me because I cannot see him homeless and I cannot get help from any State bodies' (Parent, survey). Life partners report significant challenges in providing care and support, emphasising the urgent need for health professionals to acknowledge the long-term stress: on relationships 'It was so difficult to cope, I thought I was going mad. The arguments went on and became very intense. He has not had a steady job since we got married, until now, and still, he constantly talks about leaving the job, and he flares up if I argue back'. PDA adults repeatedly emphasised the need for greater acceptance of the way in which they experience and view the social world, and consideration of the consequences of imposing rigid structures of support or categorically specific models of service provision.

Conclusion

Quantitative and qualitative findings from the survey, in-depth interviews and focus groups provide substantial evidence for the adoption of an individualised approach to supporting people who present with complex profiles across diagnostic categories, including those who experience PDA. The importance of a flexible, transdisciplinary, and coherent approach to assessment and service access extends across all aspects of human life (personal, social, educational and health). Education and healthcare practitioners – be they teachers, psychologists, therapists, psychiatrists – must engage in the skilful use of professional tools to identify the most appropriate solutions relative to the context and community of the individual. Utilising a reflective practice approach, collaborating with colleagues through sharing knowledge and recognising that not all interventions or supports are appropriate for all individuals is in line with contemporary best practice. Our findings suggest that a flexible, informed and individualised approach to assessment and service provision for individuals presenting with this particular profile is crucial. Practitioners with expertise and experience in supporting CYP with a PDA profile universally referred to the necessity for a streamlined, integrated and collaborative multidisciplinary approach.

The reported disconnect between education and health system in terms of assessment and consequent support or intervention is a very important finding in the present study. The upskilling of education practitioners and health providers in the knowledge and understanding of atypical profiles within autism, is both essential and critical and requires additional input from multi-disciplinary teams. Practitioners who are knowledgeable and skilled in working with individuals with a PDA profile must be encouraged to share that expertise. Currently, community support groups provide much of the knowledge base to practitioners and supports to families across the country, with little or no funding or recognition.

Within the wider discussion of inclusion for people with disabilities, work is required on the reframing of difference and deficit in terms of diversity. Within the bioecological model of autism, systemic influences on education and healthcare services and society in general, have a lifelong impact. In order to progress awareness, acknowledgement, acceptance and understanding, assessment and diagnosis procedures need to be clarified and streamlined to (1) provide a clearer diagnostic pathway and (2) to avoid driving parents towards costly private assessment processes that do not guarantee access to intervention or support. The reported disconnect in the Irish system between assessment and consequent support or intervention is a very important finding in the present study. Greater recognition of the duality of autism and mental health is required by CAMHS and that bouncing parents and individuals between disability services and mental health services is distressing and exhausting for parents and their children.

There needs to be consensus that, as a profile, recognition of PDA does not necessarily require a separate diagnosis where autism has already been confirmed in that professionals are equipped with the competencies to note the presentation of anxiety and extreme demand avoidance and to signpost parents and educators towards appropriate support, intervention, services and educational placements. The nature of extreme demand avoidance is undeniably challenging for individuals and their families and the focus on PDA as a separate 'syndrome' is controversial and contested (Kildahl et al., 2021) which diverts attention away from the very real needs of individuals. Arguably, a more useful focus would be to consider the lived experience of individuals using the Comprehensive and Brief International Classification of Functioning, Disability and Health (ICF) Core Sets for Autism (Bölte et al., 2019; ICF Research Branch, 2017) to provide a unique profile of needs across the lifespan.

Critically, our findings illustrate that there are negative lifelong economic and health outcomes for the well-being of autistic individuals and families in Ireland, as a function of both the failure to recognise and understand the complexity of autism and extreme, anxiety-based demand avoidance but also restricted access to assessment pathways and consequently support avenues. Evidently, earlier intervention and support, irrespective of age or developmental stage, has the potential to create increased opportunities for success and therefore inherently more positive futures. Outputs from this study – *Evidence-informed Advice for best practice in supporting pathological demand avoidance* – have been compiled by members of the autistic community, teachers, psychologists and therapists to support parents and practitioners in primary, secondary and tertiary education, and clinical settings and are freely available to the public.

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Conflict of interest

No potential conflict of interest is reported by the authors.

Data availability statement

Data are available on request due to privacy/ethical restrictions. Outputs can be accessed and downloaded from https://www.prismdlr.com/pda-ireland.

Ethics statement

This paper is the original work of the authors and is not under consideration or published elsewhere. The paper reflects the authors' own research and analysis in a truthful and complete manner.

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